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Report of the Washington Group on Disability Statistics

Note by the Secretary-General

In accordance with a request of the Statistical Commission at its forty-second session (see E/2011/24, chap. I.A), the Secretary-General has the honour to transmit the report of the Washington Group on Disability Statistics. This report presents the work completed by the Washington Group as well as its workplan for 2012. The Commission is requested to express its views on the findings and conclusions of the Washington Group and the proposal for its future work. In particular, the Washington Group is seeking the Commission's approval on its workplan for 2012.

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Report of the Washington Group on Disability Statistics

I. Introduction

1. In June 2001, the United Nations International Seminar on Measurement of Disability recommended that principles and standard forms for indicators of disability be developed for use in censuses. There was a broad consensus on the need for population-based measures of disability for country use and for international comparisons. This work was greatly needed because data on disability, especially in developing countries, are scarce and often of poor quality. Furthermore, international comparability is often lacking, even among developed countries. As a result, the Washington Group on Disability Statistics was formed to address the urgent need.

2. The main purpose of the Washington Group is, therefore, the promotion and coordination of international cooperation in the area of health statistics focusing on disability measures suitable for censuses and national surveys. Its major objective is to provide basic necessary information on disability that is comparable throughout the world. More specifically, the Washington Group set a goal of developing a short set of disability measures, suitable for use in censuses, sample-based national surveys or other statistical formats, for the primary purpose of informing policy on the equalization of opportunities. A second priority is to recommend one or more extended sets of survey items to measure disability, or guidelines for their design, to be used as components of population surveys or as supplements to specialty surveys. These extended sets of survey items are intended to be related to the short set of disability measures. The International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organization (WHO) has been used as the basic framework for the development of the sets. All disability measures recommended by the group, short or extended, are accompanied by descriptions of their technical properties, and methodological guidance is given on their implementation and their applicability to all population subgroups. The Washington Group disseminates its work products globally through the Internet (www.cdc.gov/nchs/washington_group.htm) and scientific publications.

II. Progress report on work completed

A. Meetings and collaborations

3. The Washington Group has held 11 annual meetings since its inception: 18-20 February 2002 in Washington, D.C.; 9 and 10 January 2003 in Ottawa; 19 and 20 February 2004 in Brussels; 29 September-1 October 2004 in Bangkok; 21-23 September 2005 in Rio de Janeiro, Brazil; 10-13 October 2006 in Kampala; 19-21 September 2007 in Dublin; 29-31 October 2008 in Manila; 7-9 October 2009 in Dar es Salaam, United Republic of Tanzania; 3-5 November 2010 in Luxembourg; and 14-16 November 2011 in Southampton, Bermuda. Annual meetings are held in major geographic regions to facilitate participation, especially by developing countries.

4. The Washington Group has sought to foster international collaboration and in particular to ensure that the efforts of the group are broadly based and inclusive of

voices from developing countries from every region of the world. Thus, representatives of national statistical authorities, disabled people's organizations and other international organizations participate in the Washington Group. Since its inception, representatives of national statistical offices in 123 countries have participated in the Washington Group. Representatives from 89 countries have attended at least one annual meeting, and representatives from 58 countries have attended more than one annual meeting. Current members of the Washington Group include 118 national statistical offices, 7 international organizations, 6 organizations that represent persons with disabilities, the Statistics Division and other United Nations affiliates (see annex I).

5. The Washington Group has worked with the Statistics Division, WHO, the Economic and Social Commission for Asia and the Pacific (ESCAP), the Economic and Social Commission for Western Asia, the Economic Commission for Europe (ECE), the International Labour Organization, the Organization for Economic Cooperation and Development, the Inter-American Development Bank, the World Bank, Eurostat, the Norway-based research institute SINTEF and others to promote a unified approach to disability measurement. Several World Bank data instruments in India and Uzbekistan have been heavily influenced by the work of the Washington Group, and SINTEF has been working in Africa to conduct independent tests of Washington Group questions. The Washington Group has also been informed that its question set has been pretested or added to surveys in more than 30 countries. The Washington Group continues to work with the World Bank in matters of common interest and in attempts to secure funding for further activities related to the testing and development of extended sets of questions on disability in other regions.

6. The Washington Group continues to collaborate with ECE, WHO and Eurostat on the Budapest Initiative on Measuring Health Status. The final version of the Budapest Initiative's question set on health status was adopted in November 2010 at the joint meeting of the Washington Group and the Budapest Initiative in Luxembourg and subsequently presented to Eurostat — as part of the Budapest Initiative — for inclusion in the next round of the European Health Interview Survey.

7. Discussions have continued with ESCAP to explore the development of an implementation project. The Washington Group continues to seek the support of the World Bank in continuing the development of disability measures. Discussions have been held with the Department of Social and Economic Affairs regarding the use of the Washington Group questions for the purpose of monitoring the Convention on the Rights of Persons with Disabilities. New contacts have been established in the Middle East with the Arab Institute for Training and Research in Statistics (AITRS).

8. At the eleventh meeting of the Washington Group a more formal collaboration was arranged between the Washington Group and the United Nations Children's Fund (UNICEF) regarding the development of the extended sets of questions on child disability.

9. WHO and the World Bank, in its *World Report on Disability* launched in June 2011, proposed the following recommendations to enhance the availability, comparability and quality of data on disability, which reflect directly on the work of the Washington Group:

- That improved national disability statistics be incorporated into national statistics programmes through the routine collection of disability data
- That appropriate tools — quantitative and qualitative methodologies — be developed to improve and expand data collection on disability
- That national population census data be collected according to the recommendations from the Washington Group on Disability Statistics and the Statistical Commission
- That the questions developed by the Washington Group and the Budapest Initiative be used to provide a core set that can be expanded to meet country needs
- That extended measures of disability be developed and tested for use in population surveys or as the core of a disability survey, as initiated by the Washington Group and the Budapest Initiative
- That national statistical offices be encouraged to actively participate in the Washington Group as a means of improving data quality, comparability and availability

10. A representative of the Washington Group participated in the world release of the report at United Nations Headquarters in New York in June 2011 and in the release of the report in the United States of America in Washington, D.C., in September 2011. The Washington Group is committed to addressing the recommendations of the report. As noted below, the 2012 workplan contains items that address the use of the short set questions for data collection and the analysis of the resulting data.

B. Recent activities and major achievements

1. Question development

11. A major accomplishment of the Washington Group has been the development, testing and endorsement of a short set of questions that can be used on censuses and surveys. At the sixth annual meeting of the Washington Group in Kampala, test results from 15 countries (see annex II) were reported and the short set of questions on disability was endorsed by the 23 countries and 5 international agencies in attendance. The set comprised questions on six core functional domains: seeing, hearing, walking, cognition, self-care and communication. These questions were based on the model of disability inherent in ICF and contained a particular emphasis on international comparability. On the basis of information obtained from the country reports submitted by the primary country representatives between the ninth and eleventh meetings of the Washington Group, 31 countries indicated that the short set of questions, or some variant thereof, were included in the recent census round. Testing procedures designed for the evaluation of internationally comparable question sets were developed for the use of the Washington Group. The testing procedures include both qualitative — cognitive testing — and quantitative methodologies. Training and technical assistance has been provided to countries with regard to conducting the Washington Group tests and, more generally, with regard to disability data collection methods.

12. The Washington Group has also developed an extended set of functioning questions to be used as components of population surveys, as supplements to surveys or as the core of a disability survey for use in surveys that expand on the short set. In collaboration with ESCAP, the Washington Group conducted standardized cognitive testing of the extended question set in nine countries (Cambodia, Canada, Kazakhstan, Maldives, Mongolia, the Philippines, South Africa, Sri Lanka and the United States). Standardized field testing of the extended question set was conducted in six countries (Cambodia, Kazakhstan, Maldives, Mongolia, the Philippines and Sri Lanka.

13. In February 2011, an expert group meeting was held in Bangkok to review the results of a second round of cognitive testing of the Washington Group/ESCAP extended question set to measure disability through surveys. The objectives were to discuss the results of the second round of cognitive testing, particularly with regard to the domains of communication, hearing, affect, pain and fatigue; to further train senior statisticians from the Asia-Pacific region on the skills required to undertake the analysis of cognitive interviews; and to discuss future areas of work on disability data collection and measurement.

14. In collaboration with the Budapest Initiative, a final version of a question set on health state — a subset of the extended set on functioning — was submitted to Eurostat for inclusion on the European Health Interview Survey.

2. Workshops and technical assistance

15. In August and September 2009, at the request of the World Bank, the Washington Group assisted the Bangladesh Bureau of Statistics by holding a training workshop designed to provide an understanding of disability and functioning using the ICF-based Washington Group approach and by implementing the Washington Group short set of questions in the country's national Household Income and Expenditure Survey and in preparation for the 2010 census.

16. A regional workshop was held in collaboration with ESCAP in December 2009 in Bangkok. The workshop aimed to increase participants' knowledge of the implementation of cognitive and pilot tests for questionnaire design by disseminating the results of the cognitive and field tests of the Washington Group/ESCAP extended question set to measure disability through surveys, and to further advocate the ICF-based approach for disability data collection through training on census and survey data collection.

17. In July 2010, the Washington Group held a workshop in collaboration with ESCAP that focused on training country participants in cognitive survey methods and presented the results from the disability study's pilot and cognitive tests. The workshop was attended by representatives from national statistical offices in Cambodia, Kazakhstan, Maldives, Mongolia, the Philippines and Sri Lanka.

18. A training workshop for question evaluation and cognitive interview methodologies was held in Muscat in October 2010. The objectives were to inform researchers of, and train them in, current cognitive interview methodology and question evaluation techniques with respect to the Washington Group extended set of disability questions. The workshop was hosted by the Ministry of National Economy and was attended by 15 representatives from the national statistics offices of Egypt, Jordan, Morocco, Oman, the Sudan, the Syrian Arab Republic, Tunisia, Yemen and Palestine.

19. In December 2010, AITRS sponsored a disability seminar in Damascus. Its specific goal was to share knowledge with representatives from national statistics offices in Arab countries on disability definition and measurement. The seminar was attended by 22 representatives from the national statistics offices of Bahrain, Egypt, Iraq, Jordan, Libya, Morocco, Oman, the Sudan, the Syrian Arab Republic, Tunisia, Yemen and Palestine.

20. In May 2011, representatives from the Washington Group secretariat participated in a training workshop sponsored by AITRS in Sharjah in the United Arab Emirates. Its aim was to train representatives from national statistics offices in Arab countries to understand and operationalize disability measures developed by the Washington Group. The training workshop was attended by 35 representatives from the United Nations Relief and Works Agency for Palestinian Refugees in the Near East and from the national statistics offices of Bahrain, Djibouti, Egypt, Iraq, Jordan, Kuwait, Lebanon, Morocco, Oman, Saudi Arabia, Somalia, the Sudan, the Syrian Arab Republic, Tunisia and the United Arab Emirates.

3. Current activities and the eleventh annual meeting in Bermuda

21. The Washington Group is monitoring the use of the short set in the 2010 round of censuses. Information on the questions used and the resulting estimates of disability was requested from the Washington Group, and preliminary analyses of the country results were presented at the eleventh meeting. Of particular interest was the impact of modifications to the question set that had been made by certain countries. Discussion focused on how these findings could be used to better inform countries about the collection of disability information and the potential impact of question wording. Work in this area is part of the plan for 2012.

22. The Washington Group is continuing to work on the extended set of disability questions on functioning. The question set was added to the National Health Interview Survey (NHIS) conducted by the United States and data is now available for analysis. Preliminary findings were presented at the meeting. The discussion focused on ways in which the data could be used to better understand the question set and to provide guidance for analysis. This project was adopted as part of the workplan for 2012.

23. Two working groups — one on the development of an extended set for measuring disability among children and youth and one on measuring the environment as it relates to functioning — presented the work accomplished in the previous year. The working group on measuring disability among children and youth, chaired by members of the National Institute for Statistics in Italy, presented a well-received proposal for the development of the extended set for children that included a conceptual framework and examples of ways to operationalize it. A delegate from UNICEF attended the meeting and presented information on the survey items used in the Multiple Indicator Cluster Surveys. A formal collaboration was arranged between the Washington Group and UNICEF to work on the development of the extended set of questions on child disability. The working group investigating environmental factors, chaired by the National Center for Health Statistics of the United States, also presented its work, which consisted of a conceptual framework and related question sets. In addition, a session was held on ways in which participation could be addressed more directly. The working group was encouraged to continue work in both areas.

III. Workplan for 2012

24. At the eleventh meeting, the Washington Group agreed to its workplan for 2012. Among other items, the plan delegates specific responsibilities to the steering committee and the working groups that meet throughout the year via e-mail and telephone conferences. Next steps for the steering committee and the working groups include the following:

(a) Work on the short set questions:

(i) A working group will prepare a paper for publication reporting on the use of the Washington Group short set of questions — and other measures of disability — and the impact on the data obtained of wording changes to the standard set;

(ii) A working group will prepare a presentation on the analysis for the twelfth meeting;

(b) Work on the extended sets of questions on functioning:

(i) Interested Washington Group members will continue analyses of data from NHIS and prepare a paper for publication on analysis of the NHIS data;

(ii) The members will prepare a presentation on the analysis for the twelfth meeting;

(c) Work on extended sets of questions on child disability:

(i) The working group on child disability will continue to develop its proposal on the question set for children and develop a proposed question set;

(ii) The working group will collaborate with UNICEF on the development of the extended set of child disability measures;

(iii) The working group will prepare documents on the development of measures of child disability for the twelfth meeting;

(d) Work on extended sets of questions on environmental factors and participation:

(i) A working group will continue work on the development of the conceptual framework and develop a proposed set, or sets, of questions;

(ii) A working group will prepare documents on the development of measures of environmental factors and participation for the twelfth meeting.

25. The twelfth Washington Group meeting is tentatively scheduled to be held in October 2012 in Beijing.

IV. Points for action by the Commission

26. The Commission may wish to (a) express its views on the activities and achievements of the Washington Group as described in the progress report; (b) urge support through United Nations regional offices for training, cognitive and field testing, technical assistance and regional workshops; and (c) consider and approve the draft workplan of the Washington Group for 2012, as described in section III.

Annex I

Membership of the Washington Group on Disability Statistics

1. Current representatives from national statistical authorities include 118 countries and territories: Albania; Antigua and Barbuda; Argentina; Armenia; Aruba; Australia; Austria; Bangladesh; Barbados; Belgium; Bermuda; Bolivia (Plurinational State of); Botswana; Brazil; Bulgaria; Burundi; Cambodia; Canada; Chad; Chile; China; Colombia; Côte d'Ivoire; Costa Rica; Croatia; Cuba; Cyprus; Czech Republic; Democratic Republic of the Congo; Denmark; the Dominican Republic; Egypt; Estonia; Fiji; Finland; France; Gambia; Germany; Ghana; Greece; Guatemala; Hungary; India; Indonesia; Iran (Islamic Republic of); Iraq; Ireland; Israel; Italy; Jamaica; Japan; Jordan; Kazakhstan; Kenya; Kuwait; Kyrgyzstan; Lao People's Democratic Republic; Latvia; Lebanon; Lesotho; Lithuania; Luxembourg; Malawi; Maldives; Malta; Mauritius; Mexico; Micronesia (Federated States of); Mongolia; Morocco; Mozambique; the Netherlands; New Zealand; Norway; Oman; Pakistan; Panama; Paraguay; Peru; Philippines; Poland; Portugal; Qatar; Romania; Rwanda; Saint Lucia; Saudi Arabia; Serbia and Montenegro; Sierra Leone; Singapore; Slovakia; Slovenia; South Africa; Spain; Sri Lanka; Sweden; Syrian Arab Republic; Thailand; Tonga; Trinidad; Tunisia; Turkey; Tuvalu; Uganda; United Arab Emirates; United Kingdom of Great Britain and Northern Ireland; United Republic of Tanzania; United States of America; Uruguay; Venezuela (Bolivarian Republic of); Viet Nam; Zambia; Zimbabwe; Curaçao; Hong Kong, China; Macao, China; Occupied Palestinian Territory; and Sint Maarten. In the past, the Bahamas, Comoros, Ecuador, Nigeria and Turks and Caicos Islands also participated.

2. Past and present representatives of international organizations representing persons with disabilities include the European Disability Forum, Rehabilitation International, the Inter-American Institute on Disability, the African Rehabilitation Institute and the International Federation for Spina Bifida and Hydrocephalus. Past and present representatives of national organizations representing persons with disabilities include the National Disability Authority in Ireland, the Coordination Office for the Integration of Displaced Persons in Brazil, the National Secretariat for Social Integration of the Disabled in Panama, the Disabled Organization for Legal Affairs and Social Economic Development in the United Republic of Tanzania, the Association for Persons with Cerebral Palsy in Mexico, the Puerto Rico Council on Developmental Disabilities, the Office of the Ombudsman for People with Disabilities in Puerto Rico, the National Institute on Disability and Rehabilitation Research in the United States and the National Union of Persons with Disabilities of Uganda. Past and present representatives of organizations representing persons with disabilities in Bermuda include Age Concern, Bermuda Resources for the Advancement of Children with Special Needs, the Bermuda Autism Support and Education Society, the Bermuda Society for the Blind and the Bermuda Hospitals Board, while Government organizations in Bermuda include Community Rehabilitation-Occupational and Physiotherapy Services, the National Office for Seniors and the Physically Challenged, the Human Rights Commission and the Department of National Drug Control.

3. Other international organizations that have previously participated or currently participate in the Washington Group include Eurostat, Partnership Health of the

European Union, the International Labour Organization, the Organization for Economic Cooperation and Development, the Inter-American Development Bank, the International Development Project, the World Bank, the World Health Organization, the World Health Organization Family of International Classifications Collaborating Centre, the United Nations Children's Fund, the Economic and Social Commission for Asia and the Pacific, the Economic and Social Commission for Western Asia, the Economic Commission for Europe and the Statistics Division.

Annex II

Additional accomplishments of the Washington Group to 2009

Question testing

1. In evaluating questions for both the Budapest Initiative and the Washington Group, three large-scale evaluation studies were conducted. The first study was an evaluation of the Washington Group short set of six disability questions intended for censuses. Fifteen countries took part in this study: Argentina, Brazil, Democratic Republic of the Congo, Egypt, Gambia, India, Kenya, Lesotho, Mauritius, Mexico, Paraguay, Philippines, United Republic of Tanzania, Uganda and Viet Nam. The results of this first evaluation have been published.[a] The Washington Group extended set of questions on functioning and the Budapest Initiative health state set were analysed in two separate studies: the Economic and Social Commission for Asia and the Pacific (ESCAP) study (see www.unescap.org/stat/disability/analysis) and the Granada Group Study.

2. With the backing of ESCAP, an extended set of questions was cognitively and field tested in six south-east Asian countries: Cambodia, Kazakhstan, Maldives, Mongolia, Philippines and Sri Lanka. A joint meeting of the Washington Group, the Budapest Initiative and ESCAP convened in May 2009 analysed the data and cognitive and preliminary field test results were presented at the ninth meeting of the Washington Group in Dar es Salaam, United Republic of Tanzania, in 2009. Efforts to finalize an extended set of disability questions were presented at the tenth meeting of the Washington Group, held in Luxembourg in November 2010.

3. The Granada Group, consisting of France, Germany, Italy, Portugal, Spain, Switzerland and the United States of America, took a somewhat different approach in looking at the same set of extended questions. While the group collected cognitive data from qualitative interviews and analysed it along the same lines as the ESCAP project, their approach focused on the further development of question evaluation methodology and best practices in cognitive research methodology.

Regional workshops

4. The Washington Group organized and held two regional workshops in 2005 in Africa and Latin America. These workshops were primarily directed towards countries in the region that were interested in including disability questions in their national censuses. The workshops familiarized countries in the region with the short set of Washington Group questions on disability, the accompanying rationale and the procedures for testing the questions. These workshops helped to build capacity for data collection on disability in many developing countries.

5. The Washington Group has participated in the following additional regional workshops:

- A training workshop on disability statistics for member countries of the United Nations Special Programme for the Economies of Central Asia, held by the

[a] Kristen Miller et al, "Results of a cross-national structures cognitive interviewing protocol to test measures of disability", *Quality & Quantity*, vol. 45, No. 4, (June 2011).

Economic Commission for Europe (ECE) in Bishkek, 13-15 December 2006. The aim of the training workshop was to introduce participants to the best practices on disability statistics and to develop knowledge of methodologies of measurement of the health status of the population. The workshop was organized for health statistics directors and staff engaged in the measurement of disabilities in the national statistical offices and ministries of health in Central Asia and Azerbaijan.

- A training workshop on census management held jointly by ECE and the United Nations Population Fund (UNFPA) in Sarajevo, 18-22 February 2008.

- A workshop on strengthening capacity for disability measurement across South Asia sponsored by the World Bank and a regional workshop on promoting disability data collection through the 2010 population and housing censuses sponsored by the United Nations in Bangkok in April 2008.

- A regional training workshop on population and housing censuses for South-East European countries sponsored jointly by ECE and UNFPA in Ohrid, the former Yugoslav Republic of Macedonia, in November 2008. The workshop was organized for senior professionals and experts from the statistical offices of Albania, Bosnia and Herzegovina, Bulgaria, Croatia, the former Yugoslav Republic of Macedonia, Montenegro, Romania, Serbia and Kosovo. The Washington Group was responsible for a full-day training session including the measurement of disability in censuses and interpreting and understanding disability as measured using the Washington Group short set of questions.